Measuring treatment outcomes for individuals with severe learning disabilities and epilepsy

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Epilepsy is a significant co-morbidity in learning disability and a source of considerable health loss. The prevalence of epilepsy in severe learning disability, i.e. those individuals with IQs of < 35 is approximately 40%, and their seizures are often complex and refractory to treatment.

Communication deficit is a feature of severe learning disability which impacts on all aspects of epilepsy management including diagnosis, response to treatment and outcome. People with severe learning disabilities are unlikely to be able to describe their seizures coherently or any side effects from their medication, in this population, behaviour often replaces language as the main communication tool.

The aim of the project is to offer a framework for assessing the effectiveness of treatment in terms of seizure control, side effects of medication and the impact on the individual quality of life. The methodology includes the use of assessment tools of proven efficacy and direct observation. The involvement of the individual and their carers is central to the process.

Audit of a fast-track one stop clinic for patients with new onset seizures, very useful, not too expensive, but creates its own problems

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Following discussion with General Practitioners about their needs (and audit of their epilepsy care) we set up a fast-track clinic for seeing patients with new onset seizures quickly. We try to see patients within 2 weeks of referral, assess them thoroughly and carry out investigations, such as EEG and MRI, at this first visit (One Stop). They are then seen with the results by the Consultant 2 to 3 weeks later and a decision made about diagnosis and treatment (sooner, if seizure frequency is increasing).

Audit of the first 200 patients seen in the clinic and followed up for at least 1 year reveals that only in approximately one-third of patients can epilepsy be diagnosed at first contact: in a third, it is clear at first contact that epilepsy is *not* the diagnosis (anxiety, syncope etc.), and in a third a definite diagnosis cannot be made and the clinician has to wait for further developments. In only half of these 'wait and see' patients does the diagnosis make itself clear within a year. 'Wait and see' and non-epilepsy proportions have been increasing, suggesting that General Practitioners are using the clinic differently now to how they were using it at the beginning.

The advantage of the clinic is that epilepsy is diagnosed and investigated early and treated quickly and in a cost-effective way.

The disadvantage is that the clinic accumulates patients with non-epilepsy who still require management (which the General Practitioner will expect) and a number of patients waiting for their next seizure. We need to develop a management strategy for these patients and make better links with General Practice so that most of the follow-up care of the patients with epilepsy can be carried out in the primary care setting to avoid patients accumulating in the clinic and clogging up the system.

Our experience suggests that the first visit can be managed by an experienced trained clinical nurse operating an assessment protocol, thus freeing up consultant time for the important second visit.

Teaching epilepsy to medical students: developing special study modules

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For some years now in Birmingham University Medical School epilepsy has been used as a model (in the second year teaching on medical psychology) to illustrate mind/brain relationships, stigma, observational skills, history-taking, the effect of stress, psychosomatic illness and sickness behaviour.

Recent changes in the medical curriculum instigated by the General Medical Council have led to less core teaching and more self-directed special study teaching of specialist subjects. We report on three special study modules on epilepsy (approximately 50 students in total) run in the last year at Birmingham Medical School by members of the University Seizure clinic. We describe the lessons learnt in running these highly successful and over-subscribed courses which have enabled us to introduce many students, who otherwise would have qualified with little knowledge of it, to the fascinating subject of epilepsy which can only be good for epilepsy itself. Student projects, uniformly of a high standard, have ranged from sudden death, through women's issues, learning difficulties, pharmacology, and children's epilepsy to alternative therapies for epilepsy.